

Framing Nancy Mairs: A Documentary Project

Janice L. Dewey, Ph.D.
University of Arizona

Abstract: This article is an interview and conversation between disability activist and writer Nancy Mairs, and videomaker Janice Dewey. They discuss the making of a documentary about Mairs' life and explore intersects between writing, film, and disability.

Key Words: Nancy Mairs, documentary, arts and disability

Most readers familiar with the academic and literary terrain of disability studies know the creative non-fiction work of Nancy Mairs. Her foundational essay, *On Being a Cripple*, is included in *The Norton Reader: An Anthology of Expository Prose*, a tome carried to college classrooms across America and certainly abroad wherever English is the dominant language used in formal education. Mairs writes "through" her multiple sclerosis-disabled body and wheelchair perspective on the world in all seven of her books of essays, most notably, *Waist-High in the World: A Life Among the Nondisabled*.

The recent publication of, *A Troubled Guest: Life and Death Stories* (Beacon Press, 2001) continues Mairs' remarkable production of literary and theoretical work, a body, if you will, that represents a seamlessly integrated world: memoir, politics, theology, philosophy, feminism – all the many sight lines and fault lines that allow us to acknowledge and question the human condition and experience. How do we live? How do we die?

In these essays Mairs marks the inevitable passage into what can no longer be deferred: conscious awareness that indeed one is going to die, in large part due to the deaths of one's parents.

There is no one standing guard anymore (as there truly wasn't anyway) on "generational watch." The path ahead toward death has been completely cleared of those who lead us there. The intensely personal and detailed meditations the writer presents with renowned elegance, intelligence, and wit-full turn of phrase cover her own attempted suicide, the deaths of her father, mother, and step-father, the murder of her son Ron, the importance of creature love and the despair and praise born of pets' passing, the philosophical and political complications of the death penalty. In her opening essay, *A Necessary End*, Mairs writes: "Without death to round our little lives, they have neither shape nor sweetness nor significance... Death makes us who we are" (pages 2, 7).

Nancy Mairs: Waist-High in the World is the title I've borrowed for my hour-long interpretation of the writer's life and work. A digital video made over a 5-year period, the visual narrative unfolds through short sequences to interpret a spectrum of Nancy's extraordinarily ordinary disabled life, a writer's life. I've known Nancy for 23 years. We met in graduate school on our journeys toward a Ph.D. in English and Spanish, respectively. Many years ago, as if the proverbial light bulb switched on, I thought, "Someone should make a film of Nancy Mairs." I couldn't have known then what I now know - I would make my film insight into a significant educational expansion of the study of Mairs' literary and political work. With this film viewers, whether they have

read her work or not, glimpse Nancy's whole body and voice - a sensual articulation - through one woman's presentation of a longtime friend.

Following is an interview/conversation I had with my always-agreeable film subject in late 2001:

J: One thing I've never talked to you about, but perhaps has been transferred into the documentary, is that I've always been aware that one of the wonderful qualities about you, besides personality, is a whole sensuality that is there for someone to move into because you're disabled.

For almost as long as I've known you I've cut food for you when we eat together, I sit very close to you, move your hand; I've always felt as a human being that I've been invited to be more physical, even sensual. It's an invitation to come into your personhood, perhaps.

N: Well, it isn't an insistence. Sometimes I've felt that I've forced people into my world, but the pragmatics are that I can't do things for myself and therefore have to get people to do them. It's a question of what spirit one does this in. I guess it would be possible to set up some kind of distance, or master-servant relationship, remoteness, so that the caregiver becomes kind of an object rather than another person. For me, the person who's cutting my food is also a person, someone I'm interacting with, talking to, being with.

I would go nuts if I couldn't do that with people. I think that's why I don't like having PCAs [Personal Care Assistants].

J: What's the difference between a PCA and having Sally (sister) or George (husband) or me (friend) around? Besides the fact that you know us?

N: I know all of you but it's more than that. There's an intellectual component. I had a wonderful PCA who was terrifically useful to me and I really appreciated that. There was something missing in the relationship that I really value, a level of intellect.

I no longer have this caregiver and it puts me into a terrible bind right now because I know I must get another one, and keep putting it off and putting it off, for I would much rather have George take care of me. But that means it will take its toll on him and he doesn't get much of a sense of freedom. Oh he goes off, but I can't suppose he can keep me out of mind. Most people just go off and leave each other, they don't worry about the other when they're not together. The thing about George is...when he's taking care of me...I can be almost as alone as when I am by myself. And I guess for me that's the nature of intimacy, you know, you don't feel obliged to interact and can be spontaneous. And if you say anything you know there will be a response based on shared life, shared memories, shared cats.

J: Again, there's something present in the relationship between disabled and abled that is missing in able-bodied to able-bodied relationships. Some quality.

N: As a society we are really resistant to any of that kind of "helping," we're so independence oriented..."I can do it myself"... and there are people with disabilities like that. I don't know why it is more possible for me to say, "I can't do it myself" than a lot of other people with disabilities, but I can. I suppose I don't see my disability as a personal fault. I never have.

J: That's a central thesis of your argument about disability.

N: A lot of people do and they are encouraged to, that's the general social attitude toward any sort of difference: it's a personal fault; it's a shortcoming of some sort. For some reason I've just been inured to that. It doesn't make sense to me. I didn't do this on purpose.

J: Let's talk about the history of this project. It was a long time ago when I thought, "someone should make a film of Nancy Mairs." Then, eventually, I started looking for people to accomplish this idea, thinking that I could be involved in some way. I met Jeff Imig, and he said, "My job [at the University of Arizona] is to teach you how to do this." And you, very graciously, allowed yourself to go into the experiment.

N: Well, I'm a teacher at heart.

J: There's an interesting question about this project that's related to what people often ask you - they wonder about how you use your family as your subject matter and present them in a highly personal way. You disclose a lot.

I've often been troubled myself about how this documentary uses you for a large project that will benefit me academically. I feel this use to be exploitive and thus some kind of contamination, even though the project is a creative and educational one.

N: This question doesn't trouble me. Why don't I feel that barrier around privacy that many people do feel? Maybe it's because I've been so cut off in the first place that I don't erect borders/barriers...I've always been behind some kind of wall or secret. So this openness to write about the interior world maybe comes from a sense that no one is listening, so it doesn't matter.

J: But you've become such an intimate writer, a writer about intimacy.

N: It's what I know; it's what I can do. My mother always wanted me to write a novel. I knew it was because she wanted me to write something that was made up, instead of something that was about the family. George and Matthew (son) want me to write a novel too; they love novels as I do. But I've never really wanted to write one and I guess it's because I think this is something anyone can do, not in a sense that it's easy or anything, but nobody else can write the books that I've written, which is why I go on working the way that I do. I can be sure that the work is my own.

J: Perhaps we could talk about "framing," any kind of camera choice made in the taping or editing.

N: That's not different from what I do as a writer.

J: What might be distinguished between how writers frame and videographers frame, that is framing an essay versus framing the visual?

N: Another question might be, what is lost in the process of framing, film or essay? You know, whenever I finish an essay or even a whole book I think, "Well, that's not it." No matter what I do it's not going to be enough, not going to be the whole. The same for you. You're not going to "get" Nancy Mairs. Not even if you shot 100 hours...

J: No, it's not reality TV, nor is "reality TV" ever reality.

N: Maybe the essential truth is we don't know what reality is... we, as humans, frame continuously.

J: And we've become these sophisticated postmodern technological framers who watch TV a lot and can take in cuts, edits, at light speed. Think about September 11th. I've had so many discussions with my students about "reality" versus "pictures," horrendous pictures, and then there's that story about the little girl who called her mother into the room "to see the beautiful pictures." Her mother, quite upset, explained that

many people had died, and the very young girl started crying and said, "But still, they're pretty pictures."

N: But I have always seen the world as beautiful pictures and seen the world as stories, and I don't think I'm unusual in that regard. I remember talking to Barbara Kingsolver about this years and years ago. We'd told ourselves since very young, told ourselves the stories of our lives, and that was the writing instinct... but think about what we leave out, and have to or we'd go nuts. The essential part is maybe pre-conscious, or a part of early consciousness, deciding to leave out what can't possibly be taken in at any given moment. I suppose that's the problem of being ADHD, a problem editing out.

J: You're reminding me of a TV story I saw last night. New York filmmakers were called in "to light the stage of the Twin Towers' tragedy." They went in with huge cranes and all the equipment necessary to light the debris field for the rescue workers as if it were a film... and one guy said that no matter how much it looked like a movie, the people carrying out the bodies and the bodies themselves did not look like actors no matter how well an actor could have portrayed the part. The whole process was awful and the imagery awful. I think we are very confused about this, in image making, for example. How can we stand to watch these images replayed? Because we distance ourselves. It's not real.

N: I can remember watching the Challenger disaster over and over. It was so beautiful.

J: A related question: what does it feel like to watch yourself in this documentary?

N: I'm sort of used to it. Video has been around for a longtime. I used to get taped while teaching. So the initial shock, sort of like the first time you hear your voice tape-recorded...that's not what you take for your voice, that's not what you think you look like. You imagine yourself something else. I don't have that shock anymore, but I do have a whole complex of feelings. I've said this about photographs and it's true for video as well, there's always a disappointment. The film doesn't make you more beautiful than you are... you're used to seeing beautiful photos, and you're disappointed in the one of you.

J: One of the reasons this video comes alive is because you are so activated, enlivened, as a body in a wheelchair... I've watched you come down from the trees so to speak, from Nancy walking into Nancy in a wheelchair. You inhabit space very beautifully. It's one of the attractions involved in learning your story: your grace and your face and how you compose yourself.

In the documentary you present the case of a man with MS who has resigned himself to the wheelchair (eventually, and with reluctance) but refuses to take anti-depressants.

N: It was interesting, we (George and I) went to a gathering of alternative education-type people and this man greeted me alright, but stayed as far away from me as he could. He didn't want to have any contact.

J: Now here's a man with disability that will not want to see your film.

N: No, he'd hate anybody who occupies disability in a rather passive fashion - don't know if this is the right word - I'm not particularly passive, but I am passive physically, and "passive" is suffering-related. I'm willing to acknowledge the dimension of suffering that's come with MS and that's something a lot of people with disabilities hate, won't do. They deny that they have any (suffering, disability).

There are a lot of people with disabilities who think "we're not disabled" and there's a whole political contingent of people with disabilities who say "if society didn't erect all these barriers, if society provided plenty of ramps, interpreters, Braille, and all of that we'd be just fine."

I'm all for accommodation and as much as possible but I cannot believe that my life would not have some lack I directly connected to my disability.

J: Your essays (particularly in *Waist-High in the World*) suggest much to think about with regard to the disabled body in the non-disabled world, that it is but one more difference we've got to acknowledge within the diversity of human experience... the difference created by the entry of the disabled into the non-disabled world.

N: Even with all the changes, ramps, space considerations, etc., I still don't have an able body, because of my disability, not because of society's failure to build enough ramps. That's particularly true and evident when my grandchildren are around. I can't scoop them up because I can't... that's a kind of suffering that can't be compensated for. I'm suspicious of people who reduce their disability to a series of compensations... like that would be enough. I think they're emotionally stopping at some point before the fullness of reality when they say that. But it's definitely from a disability rights point of view "un-PC" to acknowledge suffering.

J: What would you hope an audience could take from seeing this video documentary?

N: I haven't thought about this.

J: Well, I can say what I would like people to get. I want them to receive the visual world that you present so beautifully in words in your own work, especially since it is so personal. I immediately thought it would be a good educational tool when teaching your essays.

N: There are films about writers that I've seen used in conjunction with their work. It always does add a dimension to the whole person, but a glimpsed person. It's more than you have without it. I've always been sad that Virginia Woolf died too early for video... I think there is a sound recording of her done by the BBC. A film is not a substitute at all for the work, but a supplement, it's like going to Monk's House and seeing the studio in which she wrote... it doesn't explain the work or necessarily illuminate any particular work, but it integrates the work of the person. I always look at the photos on jackets of books.

J: Yes, something there animates the life of the person. It also satisfies some desire to know something about the life of the writer behind the work.

N: My mother brought me a rose I still have somewhere that she had plucked from Isak Dinesen's garden, so even an object... but I don't know if I'm able to explain that, there's something mysterious about it... because obviously that rose has nothing to do with Isak Dinesen, and yet I was moved by it.

J: I have a maple leaf from Emily Dickinson's front yard... perhaps this is about making contact in some way. You write very eloquently about reading and what reading does for the reader, how it creates a world... so now you have this rose or leaf that you connect to that world. With this video your writing is given your own voice and particular accent.

N: And a world. Barbara Kingsolver talks about people asking her how to get to a town in *Animal Dreams*, a town she completely made up. So people will enter any world, a real world or not. We do that all the time.

J: Let's get back to that earlier question: what do you suppose someone who has read your work would take from this documentary? Lots of fans show up at your readings, your "gigs," as you say. And they show up in the damndest of places. What would a fan get from this?

N: I guess a sense of connection.

J: You're eminently "connectable," I know that about you. However, some might have that odd reaction to you due to your Northeastern Yankee accent - it can be a class marker.

N: Oh, definitely. I don't think I was aware of that until I went to a presentation on Old English when I was first in graduate school... a paper read by a Southern scholar... and I found myself totally disengaged from it because of the Southern accent, and then I thought, "Wait a minute! This is an expert in Old English poetry and of course knows what he's delivering despite the accent"... and then I thought "well, my mother did this to me. She reared me with that "not our kind, dear"... right out of the Preppy Handbook, which was all about my life: Eastern establishment types, WASPS.

J: This is important about the video, too, because those who would, like you, respond to your accent as you did the Southerner, I hope can see that your accent is not you. It's not you in any of your writing.

N: No, inclusivity is one of my strongest values, and it's not condescending... it's soup kitchen, Catholic worker, really believing... you know the story about Dorothy Day told by Robert Coles... he went to see her and she was deeply engrossed in conversation with a woman who was really mad, schizophrenic, and Dorothy interrupted the conversation and looked up and said, "did you want to speak to one of us?" She did not assume that the person had come in to speak to her. I can't claim to have achieved that level, but it's ultimately desirable. I see myself in relation to that... my goal is to experience, act, in a manner that says, "I'm just like others." I want people to know I'm more like them than the "odd duck," that they can identify with me in some way.

J: Are there any particular cuts or sections in the documentary you react to in any specific way?

N: Well, I certainly notice how crippled I am, appallingly crippled. And now I'm even more crippled. So shock is always one of my reactions to seeing the video.

J: This reaction is very much the substance of what you write about, a foundation for your thinking and writing, Nancy disabled in a non-disabled world.

N: Yes, but this is different than talking about it or writing about it. It concretizes disability...in the abstract I'm still very crippled but I don't have to look at it.

J: What do you see that you don't carry conceptually within you? Is it very particular, your feet or your hands?

N: No, no, but it is perhaps posture and gestures, the awkwardness of how I do things, my weakness. Interestingly, when George watches the video he isn't affected this way for he sees me all the time. But George is funny. He thinks I look beautiful. He dresses me and then he looks and says, "You're such a good-looking woman."

J: Aren't you glad you still hear that?

N: Just amazed, since I was 17 when we met and now I'm 58!

J: One thing the video can do for readers is present George...you write about him so much in your essays.

N: Yes, people always ask about George. One time a reporter from the Tucson Weekly was here interviewing me and George walked in... She said, "Well there's George; I feel like I've stepped into a novel." He was a character who had come to life.

J: Here was a journalist thinking of your non-fiction as a whole personal world. You elaborate in a highly writerly way.

N: Yes, I'm a literary writer who "literizes," makes literary, everything.

J: You come through your writing very much as a character, a consistent "body in the world, voice in the world" observer, and give us so much about your whole spectrum of feelings, how you act, what you see.

N: I'm a character all right. One of the advantages of getting old is the sense of the time things take, so when I don't like something I assume that I don't like it at this point. I no longer assume that I don't like it absolutely. Two decades ago I went to Bread Loaf Writer's Conference and was just miserable, and a shift took place there into an understanding that it was all right to be miserable. The same with a project like this. If it's not going well maybe it's not going well now, but later... We're a society so driven to have everything right and right now. It's just not the way things really work. Failure is much more common and much less terrible than people tend to think.

JANICE DEWEY <jdewey1@mindspring.com> is a professor in the Humanities Program at the University of Arizona. She holds a Ph.D. in Spanish with emphasis on Latin American literatures. Her work with Nancy Mairs has moved her into the world of disability studies. The documentary will be a valuable educational tool in the discussion of Mairs' work and disability issues in general. Dewey is also a poet with a recently published chapbook, *The Daybreak and Willingness Club*.

The DVD version of this documentary is available for purchase.

Correspondence regarding this manuscript should be sent to jdewey1@mindspring.com, subject line, Mairs Movie. In addition to the one-hour documentary the DVD features Mairs reading a chapter from her latest book: *A Troubled Guest: Life and Death Stories*, plus other features. VHS available on request without additional features.